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ABSTRACT

This report provides an account of the discussions and issues from a symposium held by the International League of Societies for Persons with Mental Handicap in November, 1984. It describes: (1) the role of voluntary organizations in the future; (2) the need for strong advocacy of the organization's goals; (3) the issue of whether voluntary organizations should be service providers, service obtainers, change agents, or monitors of quality; (4) the need for involvement of more parents, more mentally handicapped, more professionals, and more members of the public; (5) the importance of planning for future development of the organization; and (6) the question of leadership. (JDD)

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Looking Forward

Report on an ILSMH symposium on the future role of voluntary associations. Madrid, November 1984

By Ann Shearer

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International League of Societies for Persons with Mental Handicap

Looking Forward

Report on an ILSMH symposium on the future role of voluntary associations

Madrid, November 1984

By Ann Shearer

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Foreword

What is the role of voluntary organisations in the future? How can they strenghten and develop their work at a time of economic recession? How, indeed, can they survive at all?

These were among the themes of an intensive three day symposium held in Madrid in November 1984 for the leaders of voluntary organisations in our field. Among the issues we discussed were:

- influencing policy makers in the most effective way,
- assuring the quality of services,
- involving more parents, more persons with mental handicap, more professionals, more friends,
- recruiting more young people into our societies,
- helping societies to realise the value of organisational development.

The seminar was just a first step on the part of the League in helping societies to share ideas and experiences on how they can work most effectively to advance their aims.

The next step will be taken in April 1986, when a second seminar will take place in London, kindly hosted by our English member society, MENCAP. The theme of this seminar will be *"Safeguarding the Quality of Services"*.

A further follow up seminar will be held just before the League's 9th World Congress in Rio de Janeiro in August 1986. The first day of the congress itself will have "Voluntary Organisations" as its theme, and will draw on the discussions in Madrid, London and Rio.

The League firmly believes that all societies, whether large or small, can usefully consider the advantages of working in a more systematic and planned manner. But more systematic organisation and planning are only useful if there are clear goals and aims which have been well discussed and agreed among the members and leaders of the societies. The main goal must always be concerned with the need to improve the situation for persons with mental handicap and their families.

Because these issues affect voluntary organisations in all countries, and are relevant to human needs other than mental handicap, the League asked Ann Shearer to attend the Madrid meeting and to write an account of the discussions and issues as she perceived them.

We hope this report will help you to consider the work of your own organisation and ways in which it can work even more effectively in the future.

Victor Wahlstrom
Secretary General

We Have to Fight!

The associations which make up ILSMH are in many different phases of development. Some provide services, with or without government funding; others above all act as advocates, to ensure that services are provided by government agencies. There are philosophical differences, too: some associations are committed to a fully integrated educational system, for instance, while others are not sure that this is the best way ahead. But whatever the differences between ILSMH's members, Gunnar Dybwad, immediate past president of the League, was clear about what unites them: they all have to be fighters.

"The 8th ILSMH World Congress in Nairobi: There they were, that marvellous group of self-advocates, from eight different countries, speaking different languages, facing an audience of 700 people from 70 different countries around the world. Those of you who were there will remember with what clarity they conveyed to us their beliefs, their hopes, their wants, and how effectively they later on answered questions put to them from that audience. Their concerns, indeed their future, are certainly worth fighting for.

"A hospital nursery: A newborn infant with Down's Syndrome needs routine surgery, but the doctor and the parents have agreed to refuse this child the life-saving surgery because they think his life is not worth saving, because he will be a child with a handicap. England, Canada and the United States have freely admitted that those situations occur, and we may well wonder what happens in other countries. Here we face another figthing issue which deeply reflects a prejudice not just against this infant but against all people with Down's Syndrome.

"A city council is establishing new regulations: These would make it much more difficult for three or four persons with an intellectual handicap to reside together in an apartment or one-family house, even though they have lived in that city much of their life and hold jobs there. Fighting for the right of people with handicaps to live in the community is certainly a challenge facing all of us.

"Many other situations equally challenge us to stand up and fight. So let me bring you a call to arms, together with a declaration of faith – faith in our ability to sustain and widen the progress that has been made in the field of mental handicap over the recent decades, faith in the ever-growing readiness of community and society to accept persons with handicaps, and faith, above all, in the ever-increasing capacity of persons with handicaps and, indeed, with severe mental handicap, to find a place in our society.

"The forward thrust of the associations formed by parents and friends of persons with mental handicap have provided a strong base from which we all can carry on a good fight. These organisations reflect *people*:

- physicians,
- educators and psychologists,
- social scientists and rehabilitation experts,
- lawyers,
- businessmen,
- parents and friends.

"To be successful in the fight for a cause, there is need for leadership. And in that respect, our movement has indeed been fortunate."

"The 1980s: battles ahead

"*The 1940s* brought *beginnings* – of parent groups, most of them fairly closely tied to a particular service.

"*The 1950s* saw *development* – of strong national organisations.

"*The 1960s* were 'the decade of *sophistication*' – with a more realistic recognition of the immensity of the problem of mental retardation, with formation of ILSMH and the recognition of the individual rights of people with mental handicap.

"*The 1970s* brought *action* – on the Declaration on the Rights of Mentally Retarded Persons, on normalising the environment and day to day life of people with mental handicaps and safeguarding their personal dignity.

"And the 1980s?

"This will be a difficult and problematic time for all our associations, on every level – local, national and international – because we are confronted by our success and must now proceed to translate into broad programmes what has been proven by selected demonstration programmes.

"How ready are we for change?

"As our movement has grown, some of our associations maintain major enterprises with large investments, and this can decrease sensitivity to and desire for further change.

- "How are service-giving societies to set up systems of monitoring their own services and at the same time, monitoring services provided by government agencies? How to monitor and criticise the very people from whom you receive money?
- "How many societies have really seriously considered ways of making self-advocacy a political reality?
- "How to respond to the needs of the Third World?
- "How do member societies participate in the League?

Now that the League's network is spreading ever wider, involving more and more countries and vastly more people, there is danger of an increasing distance between the League and its member societies.

"The remedy lies in participation – and in particular, active participation in the work of the League's numerous committees, which represent the essence of its work.

"Nothing will more effectively prepare us for the good fight which we must wage together."

Going Into Battle: As Service Providers or Agents of Change?

"It should be one of our keenest concerns that there be *one* body which, at all times, constitutes the ultimate *independent* collective or corporate spokesmanship for those retarded persons who cannot speak for themselves . . . Only an *independent* voluntary group remains as the final bulwark of protection in front of the mentally retarded. The integrity of this bulwark must not be compromised in any fashion, because behind it there are no additional lines of defence. If the voluntary association is not free to speak with ultimate honesty and disinterest for all of the retarded at large and in the long run; or if it is beholden to a significant degree to anyone; then the retarded person cannot be assured of a full representation of his interests. But if the voluntary association cannot be free and unconditional in its militancy, then who can?"

In 1973, Wolf Wolfensberger identified *The Third Stage of the Evolution of Voluntary Organisations*[1] – the stage where the main focus of their activities was neither on providing services themselves nor on obtaining them, but on working as change agents on behalf of people who have mental handicaps.

This stage, he said, might include obtaining services, and running demonstration projects which would then be handed over. But it should also include education of the public, ensuring the rights of people with mental handicap in law and above all, monitoring the quality of the services they use.

Wolfensberger had some hard things to say about the dangers of voluntary associations continuing to provide services themselves in the long-term. He did not agree that associations composed mainly of parents best know the needs of people with mental handicaps: being so close to the problem, he thought, could prevent a larger view. He saw no evidence that the public couldn't be trusted to run high quality services: there was little relationship between quality and private or public management. He disagreed with the assertion that only voluntary associations could attract enough volunteers, although this might have some validity in developing countries: in developed ones, it was profoundly dangerous, for it encouraged the false idea (and possible self-fulfilling prophesy) that the public would never support the comprehensive services needed. He dismissed the argument that associations would only attract members if they ran services themselves.

Wolfensberger's concerns were hardly new. As early as 1949, Mr. Boyd of New Jersey identified "Three Stages in the

[1] *The Third Stage of the Evolution of Voluntary Organisations*, by Wolf Wolfensberger, published for ILSMH by the National Institute for Mental Retardation, Toronto, 1973.

Thinking of a Parent" – the stages which Wolfensberger himself elaborated. In 1958, John Fettinger gave the United States' National Association for Retarded Children (now Citizens) the slogan "Our task is to obtain – not to provide".

But a lot has changed since Wolfensberger stated his case for getting out of service provision. There have been international economic crises and the growing divide between the "haves" and the "have-nots". The United Nations, in the wake of the 1981 International Year of Disabled People, stated as a principle that states should assure the fundamental health, education and welfare of people with disabilities, and that voluntary organisations should pressure, motivate, support and develop new services which are then handed over. But how likely is that state assurance in the current international situation? Wolfensberger found no relationship between the quality of service and whether it was provided by public or private bodies. But there has been growing disquiet about declining standards in services once they have been handed over from the second to the first.

So how should voluntary associations go into battle now? As long-term service providers, as obtainers, or as change agents and monitors of quality?

Can they be the third while also being the first?

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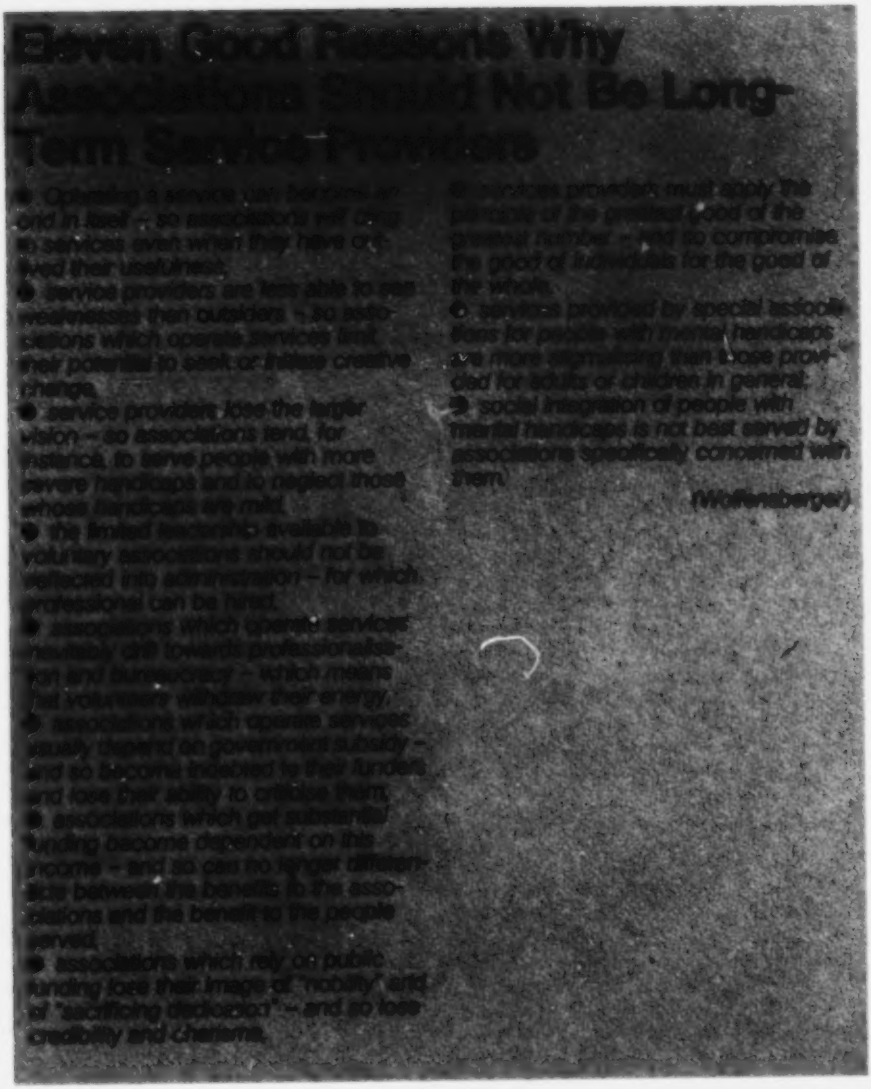


Eleven Good Reasons Why Associations Should Not Be Long-Term Service Providers

- Operating a service can become an end in itself – so associations will cling to services even when they have outlived their usefulness.
- service providers are less able to see weaknesses than outsiders – so associations which operate services limit their potential to seek out/initiate creative change.
- service providers lose the larger vision – so associations tend, for instance, to serve people with more severe handicaps and to neglect those whose handicaps are mild.
- the limited resources available to voluntary associations should not be reflected into administration – for which professionals can be hired.
- associations which operate services inevitably drift towards professionalization and bureaucracy – which means that volunteers withdraw their energy.
- associations which operate services usually depend on government subsidy – and so become indebted to their funders and lose their ability to criticize them.
- associations which get substantial funding become dependent on this income – and so can no longer differentiate between the benefits to the associations and the benefit to the people served.
- associations which rely on public funding lose their image of "nobility" and of "sacrificing dedication" – and so lose credibility and charisma.
- associations provided must apply the principle of the greatest good of the greatest number – and so compromise the good of individuals for the good of the whole.
- services provided by special schools for people with mental handicaps are more segregating than those provided for adults or children in general.
- social integration of people with mental handicaps is not best served by associations specifically concerned with them.

(Wolfensberger)

"If We Don't Provide, Then Who Will?"

For many countries, the answer to this question looks like being "No one".

For Mexico, for instance, Wolfensberger's analysis looks like luxury, when government provides only education, other services are so meagre and the economic situation is such that associations for people with mental handicaps feel they can't demand more, because they know they will be rejected. There, the emphasis for voluntary associations is on building the confidence of parents so that they can either provide services themselves or ask for government help.

For most of the voluntary associations in the Caribbean, service provision is a necessary reality of life. Even where there is government backing, as in Jamaica, the main impetus and continuity for services must come from the country's Association for Mentally Handicapped Children. After existing for 14 years with one small school and a residential home, JAMHC launched in 1970 into an extensive development programme which brought a 10-fold increase in school places, mostly in units in the regular schools. But the current severe economic crisis has meant that government support has dwindled and developments are not keeping pace with needs and demands. The record of government is not good, either, where it has started a programme with the deliberate intention that it should become a full-scale public service. An early intervention project started in Kingston in 1975, for instance, is still a project in Kingston alone, with the same budget as when it began. "The government is not prepared to remedy the ills consequent on inadequate support and the project is dying by attrition."[1]

Economic exigiencies may mean, too, that voluntary associations find themselves obliged to take on the running of services which have been an accepted state responsibility. It is written into the constitution of AKIM, the Israeli voluntary association, for instance, that it doesn't run services. But it has been forced to initiate them in almost every branch – either because the state provision was poor, or because it simply wasn't there.

So AKIM pioneered early childhood services, hostels, apartments and sheltered workshops – and then handed these over to the government. But that created a dilemma: when you know that the handover will mean a decline in the quality of the services, at what point do you stop doing it?

Now the dilemma is even more acute. The extraordinarily high level of inflation in Israel has meant that the government has asked AKIM to take back the management of many services. There is no guarantee that the money provided to run them will be enough to maintain the standards that AKIM wants to see. But if it doesn't agree, there's the danger that standards will fall even lower, and that some services might close altogether. ▶

[1] *New Trends in the Voluntary Movement in the Caribbean* by Marigold Thorburn (paper given at the Symposium).

Is the handing back of services to voluntary associations a fourth stage in their evolution that Wolfensberger did not forsee?

But in situations where associations run services because it seems that if they don't, none will, there are some high costs of the sort that Wolfensberger outlined.

If AKIM does accept the "marriage of convenience" with government, there is the danger that it will be seen as "the boss" by parents, rather than their advocate.

The expansion of educational services was exhausting for the Jamaica association. Its energies went almost entirely into building programmes. It now has administrative and fund-raising headaches.

The importance of building coalitions

For the Caribbean at least, one way out of the dilemma of associations which are major service providers lies in the building of coalitions with other disability interest groups. It became apparent in these countries during the 1970s that the size of most of them, the scarcity of resources and the common needs of these different groups would make increased collaboration welcome if not essential. The impact of self-advocacy has only strengthened this trend. As associations of disabled people are forming, the more far-seeing agencies are realising that they must join with them, and that in some areas these associations should take first place because of their greater effectiveness. Self-determination among people with mental handicaps is part of this trend.

The importance of contracts

In some countries, there's another way of trying to minimise the dilemmas of services-provision. The Scottish association, for instance, will accept government funds to run services only if this is for a definite and specified time – usually five or 10 year.

"If We Don't Provide, Then Our Associations Will Die"

In Spain, they've found that as Government starts to take more responsibility for services, the associations which used to provide them are losing their identity. They are frightened of the concept of integration, because they feel that if it's put into practice, they will be left with nothing to do.

West Germany has statistical evidence that can support the idea that an association which provides services is more healthy than one which doesn't. Lebenshilfe, the voluntary organisation, has found that overall membership, as well as the membership of parents, was very much higher, in relation to the number of handicapped people served, in branches which ran facilities than in branches that didn't.

Yet is the strength and identity of associations really dependent on being service providers? Wolfensberger thought it needn't be. And experience from the Caribbean shows he could be right.

The Jamaica association, with its considerable service commitment, found that it didn't have enough energy left to meet the emotional and human needs of parents, who tended to split off into the parent-teacher association. Nor has it had the energy to reach into the grassroots, in the poor rural areas especially.

By contrast Totolika in Curacao is perhaps the most consistently successful association in the Caribbean. It has maintained a high parent membership (60% or more), consistently set realistic and attainable goals, worked with professionals through a separate foundation which carries out project development, provided information to parents and society as a whole, and maintained an excellent relationship with government and public services. It has many family projects and is currently looking to start a pilot parent project, as well as examining new legislative challenges and the need to motivate parents to seek out or create jobs for people with mental handicaps.

Totolika, in short, seems to have followed Wolfensberger's advice about involving parents, generating public awareness and monitoring services. Significantly, perhaps, Curacao was relatively well endowed with both private and public services when the association started. So the necessity or temptation for it to become a service-provider itself was not so compelling as in other Caribbean countries.

A question:
If parents remain involved in an association which provides services, what *sort* of "services" do they want it to offer? Do these always have to involve heavy investment in bricks and mortar? Are there "services" which a voluntary association is *uniquely* qualified to provide?

Can Service-Providers Be Monitors Too?

For Austria, the answer seems to be "yes" – partly at least because of the way in which the services provided by Lebenshilfe, the voluntary organisation, are financed, and partly too because of the way that Lebenshilfe has organised itself.

Between 1964 and 1967, all nine of Austria's states passed Handicap Acts, which oblige their governments to finance services for people with mental handicaps. This legal obligation means that Lebenshilfe has felt unhampered in its advocate and watchdog role by also being a service-provider. In fact, it has always tried to impress on governments that its advocacy role has priority, and that the ability to perform it is the basis of its continued willingness to provide services. The involvement of parents as paid managers of services has not, Lebenshilfe feels, brought a drain on its advocacy activities; it expects these parent-employees to be part of them.

Lebenshilfe's structure also helps ensure that its advocacy functions don't get swamped by the demands of service-provision. These are met by the state associations, while the national Austrian association acts as a think-tank for new strategies, for political action, and for model programmes, public information and organisational development.

"Thus the advocate/watchdog function has been institutionalised and serves as a constant 'living conscience' for the state and local associations. As the state associations finance the national association, there is little danger that they will ignore what it is doing."[1]

But Lebenshilfe is aware, too, that there are dangers in the way it uses its resources. The most efficient use of its energy has more and more become a topic of discussion – and led to some changes. Most state associations, for instance, no longer build houses or other premises, but rent instead – so saving energy for their watchdog role. There is discussion now of the possibility of the association using the "franchising" model of service provision.

Questions, though, still remain. Although the association has worked hard on itself, it is aware that there is hardly any external monitoring of its services. It is aware too that it has so far done little towards the internal self-renewal of which Wolfensberger wrote. It has been so concerned to build a national organisation that it has tended to tackle issues on which there is ready agreement, rather than more contentious ones. It isn't ready yet, either, to launch the largescale membership education programme that Wolfensberger advocated. Nor are the parents pushing for it. Why not?

[1] *The Experience in Austria*, by Walter Eigner (paper given at the symposium).

NFBU (Norway)/H. Meidbø

How Can Associations Obtain and Advocate?

In Denmark, the state has been responsible for services to people with mental handicaps since 1933. But in practice this meant that the only services available were in large institutions. So one of the main tasks of the parents' association Evnesvages Vel since it started in 1952 has been to press for the development of community alternatives.

It did this by *advocacy*: In the first instance, it put pressure on the policy makers to set up the commission which resulted in the law of 1959 that started the national reform of services.

It did it by helping to *obtain* the services it wanted to see: by building kindergartens, schools and group homes which it then rented to the state to run. "By building these facilities and offering them on a turnkey basis, the parents' association made sure that the policy makers could not possibly refuse the offer, and in a very short period of time we managed to develop service facilities outside the institutions so that it became possible for many families to keep their children at home."*)

The association has continued to pursue this dual policy of advocacy and obtaining services.

On *advocacy*: It ensured that it had representatives on the central and local boards which advised on the development of services – and in most cases held the chair. When the responsibility for services devolved to the country's 14 counties, the association reorganised so that it had its own board in each county and in the two major metropolitan areas as well.

On *obtaining* services: The association has recently launched its "Alternatives to Institutions" project, through which it provides flats and houses which people with mental handicaps will rent out of their pensions. This has become possible because, as a result of the association's *advocacy*, new legislation has ensured that people who need support services in their own housing can get these as of right *and* keep their pensions – instead of having to give up their pensions to pay for services, as in the past.

The association's central board is now made up of one representative from each of the local boards, together with its member of the Central Handicap Advisory Board and the Social Welfare Advisory Board. The association has a professional staff of five, with all the rest of its work done by volunteers. It has started to look to the education of its board members; each year since 1980, it has run three different courses for them. Membership has grown to 11,000.

*) *The Experience in Denmark* by John Møller (paper given to the symposium).

Which Way for the Future? Some Unanswered Questions

The symposium's general and pragmatic conclusion was that there can be no hard and fast rules, that the role of associations would depend very much on the circumstances in which they found themselves. But that leaves some unanswered questions:

Questions of responsibility

If associations are to continue to provide services, how far are they prepared to go in this?

If, as Gunnar Dybwad said, the task of the 1980s is to translate selected demonstration programmes into broad and general ones, are associations willing to take full responsibility for this?

If so, they will become massive bureaucracies indeed! What would then happen to their role as advocates for and supporters of parents and people with mental handicaps, when they themselves have so clearly become "the boss"?

If not, how will the responsibility be shared? Are some services best run by government and others best run by the associations?

Already in some countries a trend is apparent: voluntary associations run on the whole good community services for people whose handicaps are moderate and severe, while government runs on the whole bad services in institutions for people whose handicaps are multiple and profound. This is inequitable. It also means that the people who need the most help get the least. Is this trend to become even more pronounced?

If responsibility is to be shared among many voluntary associations, who is to coordinate the services provided? How are standards to be maintained?

Questions of quality

The symposium concluded that it *is* possible for associations to be both providers of services and advocates, change agents and monitors of quality. But there are unanswered questions here too.

- How can an association credibly advocate for improvements in government services unless it is sure that its own services are as good as they possibly could be? How does it ensure that?
- How far does it systematically take account of the views of service users – parents of children and people with mental handicaps themselves?
- What objective standards is it using to assess its own services?
- What happens when parents or people with mental handicaps have a complaint against one of the association's services? To whom do they turn when their "advocates" have become the enemy? What systems of external monitoring are backing the association's own internal efforts to ensure quality?
- What happens when an association which is largely funded by government wants to criticise government services? Is it strong enough to bite the hand that feeds it? And is the hand strong enough to take it – without retaliating by cutting funds or denying the association its place on consultative bodies?

Enlisting the Allies

Getting Together

The first step is to get together with just a few others who share your concerns. They may be parents, some friendly or interested professionals such as a teacher, social worker, psychologist, doctor or other health worker, religious leader – anyone who seems interested and able to help.
This small group can meet informally and perhaps in one another's homes to share ideas. They can see if there is enough common ground and common purpose so take the next step – to form a local planning committee or action group.
(*Starting a Local Society for Persons with Mental Handicap – guidelines for action*, ILSMH, 1983)

How are allies to get together? In Jamaica, for instance, they have found that there are obstacles and contraints to overcome before they can get anywhere near the "first step"*). After a one-year project to develop parent groups in a rural area, they found that:

- Our approach must be adjusted from a "centre-orientated", inward view where "they come to us" to an out-going, community-orientated "we go to them" approach.

- We have to be responsive to the perceived needs of the community. They may have difficulty in articulating these.

- Poverty and disability go hand-in-hand, so people do not respond to overtures of help unless it is economically beneficial to them. So if you are not going to relieve them of their burden (remove the child), there must be some income-generating component to the programme.

- There is a serious and pervasive lack of appropriate information and many misconceptions about disability and disabled people.

- The combination of these tends to produce apathy or "burn-out" after a time, so it is essential to intervene as early as possible before behaviour and care burdens become excessive.

- There is a need to mobilise other resources in the community to give their help to projects *in* their own communities rather than just fund-raising to support national and highly visible programmes such as institution-building or Special Olympics.**)

*) *Starting a Local Society for Persons with Mental Handicap.*
**) *New Trends in the Voluntary Movement in the Caribbean* (paper given at the symposium).

Fundacion Centro de Enseñanza Especial

And what is true for a rural area of Jamaica can have its relevance to "developed" countries as well. There are large pockets of the USA, for instance, where people are still not reached. In approaching the poor ghettos, it's been found that if people are to "get together", they need money for transport, a lunch laid on, and someone to look after the children at home.

So the business of starting and maintaining a local society for people with mental handicap has to do with more than just gathering together a few friends. It means enlisting and meeting the needs of

- parents,
- professional workers,
- members of that world out there called "the public".

How to do this?
And what about people with mental handicap themselves?

Parents

"Now that the services are there, the younger parents just don't want to know . . ."
"We have 'organisational diabetes'. We are not reaching the younger parents. We don't feel the pain, yet the body is weakening. We have misjudged the need for emotional support of parents – which doesn't happen by itself when you provide services."

Perhaps no discussion of the future of associations would be complete without the first comment – which is perhaps losing what little credibility it may have had in countries with relatively well-developed services, as those services come increasingly under economic threat. But the second comment, from Austria, both highlights a real problem in sustaining service-providing associations and points to a way to work with it.

What makes parents into non-joiners?
Is it really that they don't care as long as "someone" is seen to be working for and providing services?
Or could it be that the associations aren't offering what parents need?

- What happens when the association provides the services and so becomes "the boss" instead of "the friend" or advocate?

As we've seen, in Jamaica they found that parents tended to split off and join the PTA (Parents-Teachers-Association), because the association was too busy building and running programmes to meet their personal needs.

- What happens when the association pushes a strategy or philosophy which is incompatible with general attitudes of society?

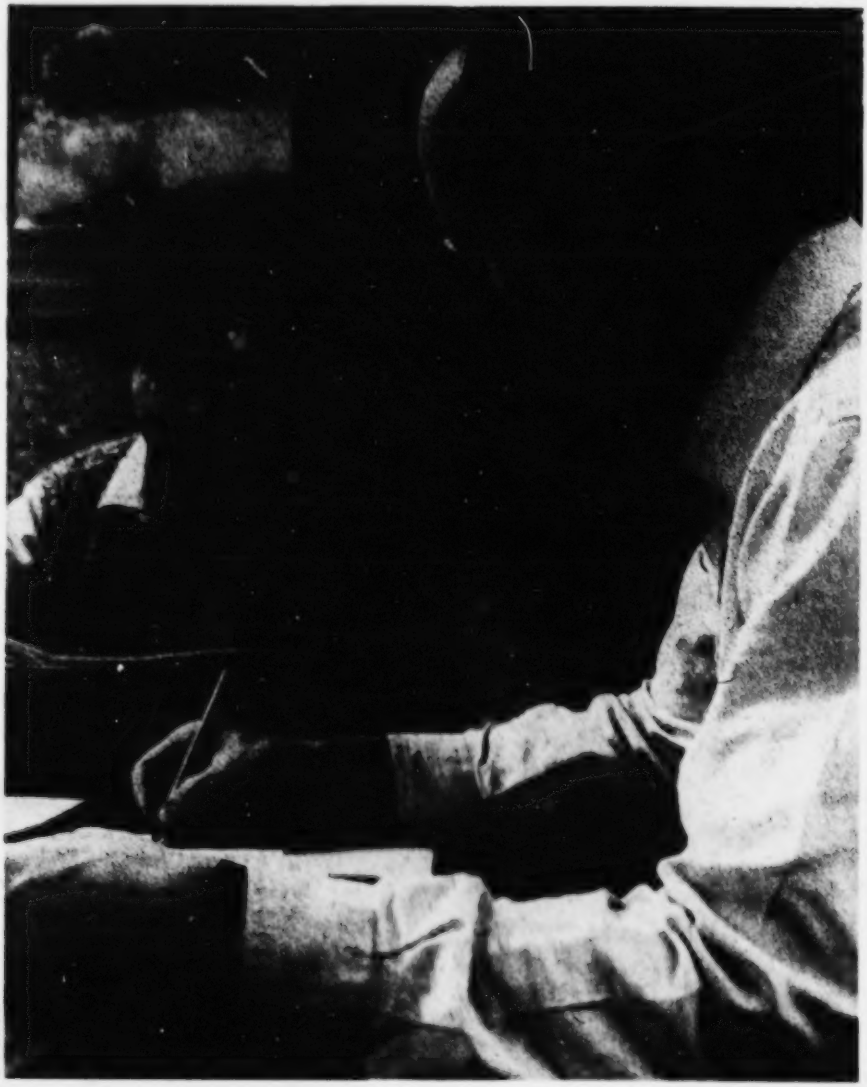
In the Caribbean, they have found that that doesn't work. The leaders have to accept that in developing countries, evolution of services, of voluntary associations and of attitudes probably parallel general development. They may have accepted normalisation and integration – but most people still probably see people with handicaps as outcasts and burdens.

- What happens when the association is run "the way we've always done it"? Young parents may have different ideas. They may want to see more integration. They may want an organisation with less rigid rules and structures and hierarchies. They may not accept the way the older parents keep the power for themselves.

- What happens when the association is so busy running services that it can't distinguish those that could be provided by others from those it is *uniquely* equipped to offer itself?

In Austria, for instance, they have recognised that they have neglected "young" parents. They are now giving priority to developing (among other services) early counselling and parent-to-parent and pilot parent programmes.

▶



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US

Parent-to-parent programmes

"If every young couple got this early intervention, we wouldn't be asking 'Where are they?' They would join our societies because they would see that they have a unique role."

So why doesn't it happen more often?

This kind of support to new parents from those with experience doesn't happen spontaneously. Parents don't automatically find each other – or if they do, the results may not always be helpful.

- There has to be organisation – while ensuring that the programme remains a "parent" one rather than becoming a "professional" service.

In the Netherlands, parent-to-parent programmes are formalised as part of the community support programme. There is a coordinator who visits all the programmes and a twice-yearly meeting of all the "support" parents. But they have found that the programme needs to keep its roots firmly in the local branches.

In New Zealand, too, they have found that they need a full-time (parent) employee to run the service – but are hoping to devolve responsibility for it to local level.

- There has to be careful selection of "support" parents and proper training for the job.

In Norway, where the voluntary societies run state-funded parent-to-parent programmes, they are careful to ensure that the pilot parents understand their own problems and situation before they take on this work. Broader training programmes for parents could be useful here too: in Mexico, for instance, they are developing training manuals for parents.

- There has to be support for the "support parents".

In the Caribbean they found that an attempt to start a pilot parents scheme fell flat when the pilot parents slipped away during their training.

- There has to be negotiation with professional people.

Doctors, for instance, may say "These parents aren't ready yet" to meet another, experienced parent. But what they may not be ready for is the *professional* opinion on their child; a pilot parent could help them reach this stage.

- There has to be sensitivity to what parents want. The best people to assess their "readiness" are the parents themselves! In West Germany, there was a lot of parent-to-parent work some 25 years ago, because there was little else. Now that there is a well-developed system of professional examinations in early childhood, they have found, parents often don't want to meet the parent of another handicapped child during the first year, because they don't yet see their own child as having a handicap.

● There has to be sensitivity to the needs of the handicapped person. A parent ist not necessarily the right person to discuss with another parent what an adult handicapped person needs.

And what about family-to-family programmes?

As more than one delegate insisted, brothers and sisters matter too! In some countries, like Kenya, the whole social structure emphasises this, as families are seen as of far more importance than individuals. Yet in other countries, the culture encourages the feeling that brothers and sisters shouldn't be "made" to feel responsible for their handicapped sibling.

But the feeling of responsibility is there – and sometimes brothers and sisters are far more open than parents to "treating the handicapped person as normally as possible". There's a growing awareness that we need family-to-familiy programmes and not just parent-to-parent ones.

The models for these may come not from the "established" association but from others. In England, for instance, Kith and Kids was set up independently of Mencap to offer family support through social events for the whole family as well as more structured programmes for the handicapped members.

Who will produce some more examples?

Professionals

"There needs to be a balance of people to serve within and represent without. It is critical for an organisation to know its membership, to identify those whose professional expertise can serve the cause. The first step, therefore, in achieving one's political aims, is to identify and attract people who have the necessary professional expertise to represent the needs."[1]

Who are the professionals? Sometimes, they can seem to be the people who

- consistently have a lower expectation of people with mental handicaps than parents and friends,
- through their diagnoses and labelling can take away from people with handicaps the identity that parents want to give them, as ordinary members of the community,
- by their presence may hinder the development of parents and inhibit them from speaking up.

But, they are also the people who

- in many countries – like Kenya, Brazil and those of the Caribbean – have taken the lead in bringing people together and even creating and sustaining voluntary associations for people with mental handicaps,
- are the ones who make sure that the policies set by volunteer committees actually get turned into action.

The antagonism between parents and professional workers is hardly new. Tensions between the two sides are still there and can be anything but creative.

Different associations live with these in different ways. Norway sees the professionals as having no part in its voluntary associations – whose strength is precisely that they are organisations of *parents*. England reckons that the best relationship between the two sides is one of equal but separate development – with a defined organisation for parents (Mencap) and another for professionals (Association of Professionals for the Mentally Handicapped) and increasing cross-membership between the two. In Canada, the Association for the Mentally Retarded sees professionals as a "resource" on which parents can draw as and when they choose. In Spain, the voluntary associations have found it helpful to work with professionals, as when the associations went to the Government and asked for one thing and the professionals went to ask for another, not much seemed to happen.

But whatever the pattern and whatever the tensions, there has to be some sort of relationship between parent organisations and professionals. After all, as one member of the symposium (a professional) said: how can you realise the rights of mentally handicapped people if you exclude from the picture the society of which they – and professional people too – are a part?

[1] *Involving Professionals to Promote our Political Aims* by Ron Major (paper given at the symposium).

So how best can parent organisations and professionals work together?

In New Zealand, IHC – the major voluntary association – is developing a deliberate strategy of involving people whose professional competance will serve its needs – and in doing so, it defines "professional" rather more broadly than is sometimes done.

Three main groups of "professionals" have been involved with IHC:

● *Members who are professional in their own field.*
These include managers of businesses, educationalists, doctors and others. They work as volunteers and leaders on IHC's committees and use their expertise both in the role of advocate and to ensure that IHC's services do what they should.

● *Professional staff.*
Their skills in delivering services, advocacy and develop mental research are essential to IHC's planning and policy implementation. They often, however, have little experience of working with people with mental handicaps, and so IHC has the job of helping them develop this professional competence as well.

● *Members who are parents and professionals.*
IHC recognises that parents are professionals: it is still a parent-directed organisation and its development of parent-to-parent programmes is a recognition of this "professional" role.

How to attract professionals?
A number of IHC branches go out and ask them to join! The fact that IHC's service operation is considerable is one factor in attracting, say, business people. IHC also makes efforts to go out and educate people – like medical and other students – not just about the needs of people with mental handicap but about the needs of IHC for professional involvement.

But it isn't always easy.

● Some professionals working with people with mental handicaps do not agree with IHC's philosophy of community services – and that can matter if they are, say, the superintendant of an institution or a professor teaching in this field. Their antagonism often stems from personal reasons: they want to ensure their own job security.

● Some professionals may ask: What's in it for me? In the past, there hasn't been much status to be gained from working with people with mental handicaps. So it's important to find "outside" professionals who have a commitment to IHC's philosophy and will support its political work. What is needed is a strategy of influence to ensure that such people get appointed to key positions.

● Some professionals may be uncomfortable with IHC's pragmatic approach to developing services. Some may be seeking "ideal" solutions; some may find the approach "unprofessional" in its lack of a "scientific" base from which it can be "scientifically" evaluated. Some may be uncomfortable with launching a programme before there is money in the bank to pay for it. So it's important for IHC to find professionals who can accept its ▶

approach and recognise that if it operated like many businesses, it would not have developed to anything like the extent that it has.

The need for strategy

Professional leadership is important when making an approach to other professionals and politicians, IHC feels; there's a need for people who can talk the language and effectively market the cause. Advocacy involves many of the skills of marketing – selling ideas, influencing policy-making and finding the strategy that will lead to the right decision. So it shouldn't be much of a step, IHC says, to involve marketing psychologists and others in helping the organisation achieve its political aims.

This demands, though, very clear goals and methods of implementation and subsequent evaluation – at local, regional and national levels. IHC is now trying to ensure that the (volunteer) president and chief executive manager in its local branches (each of which will serve some 50,000–80,000 of New Zealand's population of just over 3 million) know the key local people. It is also ensuring that its volunteer and staff people are working at the regional level at which many government services are administered. And professionals work as both volunteers and staff people to press IHC's national influence. Strategic use of professionals can have its effects – like the time when IHC wanted an increase in its government funding. It wasn't having much success through its normal channels of influence. So it asked two of its leading parent volunteers – both of whom have an "outside" management expertise and both of whom happened to be constituents of the then Prime Minister – to approach him directly. It worked.

Whatever else an association might or should do to thrive over the long run, and whatever benefit the retarded might derive from member activities, in order to "capture", motivate and hold its members, an association must also give them two things: some of its members will require affiliative and affectional support, and some members must be provided with a practical and efficient means and mechanism for satisfying the common human need to help another person, and for becoming personally and intimately involved in the lives of the retarded.

Wolf Wolfensberger, *The Third Stage of the Evolution of Voluntary Organisations*

Reaching the Public

"Good public relations cannot compensate for true action: bringing people with mental handicap into the mainstream of society."[1]

One American research study has shown that in places where a neighbourhood was prepared for the arrival of a community home for people with mental handicap through a public relations campaign, resistence grew. But where people just moved in, like anyone else, they met little or no resistance from the neighbours. So who needs public relations?

For Helmut Spudich, the idea that public relations has to do most of all with changing attitudes so that people with mental handicaps can better be integrated into the mainstream of our societies is wrong, misleading and should be done away with altogether.[1]

Attitudes, as he sees them, serve in the place of knowledge to help us make sense of a complicated world. In aspects of our life that are important to us, we have a lot of knowledge. But in aspects that aren't – like, for most people, the reality of mental handicap – we have attitudes instead. These are mostly projections of our fears as well as our wishes. So it isn't surprising that attitudes about handicapped people are negative rather than positive.

"'Changing attitudes' therefore cannot be a reasonable goal for strategic communications. Present attitudes are shaped by the fact that people with mental handicap are not seen in public a great deal and little other information is available, since mental handicap is not taught in schools and does not appear in the media regularly and adequately presented.

"Attitude change does not come about until there is a necessity to change traditional though false attitudes. Change will only happen if these traditional attitudes are outdated by the appearance of the real people and by the appearance of more adequate information about mental handicap."

So what is public relations about?

- Public relations is a process of communication within our organisations as well as outside them.

Within the organisation, it helps close the gaps between decision-makers and the "grass-roots" and make sure that all resources are used. By communication with the world "outside", it helps the organisation's development to be related to that of the society it is part of – and that's necessary if the organisation is to have lasting impact.

- Public relations expresses the goals of our organisations in relation to society at large, and so plays an important role in shaping the identity and inner development of these organisations.

[1] *Influencing Public Attitudes* by Helmut Spudich (paper given at the symposium).

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UNESCO

● Public relations offers strategies by which communcations can help promote our organisation's goals.

● Public relations is a contribution to overcoming the isolation of people with mental handicaps and building acceptance of them.

Developing a communications strategy

1. Define the target audience.
"The public" rarely exists. But association members, young parents and the medical and allied professions do. So do students, teachers, public officials and decision-makers and journalists. And so do local opinion leaders, in every culture and setting.

2. Define the channel of communications.
Don't rely simply on the press, radio and TV – whose attention many other groups are seeking and which usually preserve rather than change existing attitudes. Remember that journals, periodicals, press releases, leaflets, brochures advertisements, educational materials, meetings and exhibitions are all channels of communication. Remember that your product needs to look professional if it is to compete successfully with all the other claiming attention.

And remember that face-to-face communication plays a vital part in spreading the word.

3. Define the contents.
Two broad areas are important:
● exercising political pressure by building public support for rights, political acceptance and public financial responsibility for people with mental handicaps,
● changing personal attitudes by presenting information about the reality of people with mental handicaps.

Keep the messages clear and simple. For instance:
● Tell planners and decision-makers in government about normalisation.
● Tell parents about a local parent-to-parent programme.
● Tell medical and senior school students about new knowledge.

And What About People With Mental Handicaps?

"The full participation of persons with mental handicap in the community is a priority goal of the International League of Societies for Persons with Mental Handicap. As a result of recommendations made at the General Assembly in Nairobi, a number of persons who are mentally handicapped are serving on committees of the League and participate in decision-making.

"People with mental handicap came to Nairobi to take part in a parallel session of the League's Eighth World Congress. They recommended to the delegate body that national and local societies invite people with mental handicap to serve as committee members and board members. They also requested that national and local societies encourage and support the formation of self-advocacy groups and help them to speak for themselves and participate more fully in the community.

"Since then, there are few weeks that go by that I do not read or hear about their achievements and their efforts to participate meaningfully with our associations. It is not surprising that they are able to take part in the life of the community, to speak for themselves and to participate in decision-making. What is surprising is that we have done so little to support them in developing these skills."*)

"Our task now is to listen to them, to help them participate as equals in the life of the community and to provide them with the opportunity to make meaningful choices.

"To assert their right to participate is one thing; making it a reality is another. But the obstacles to greater participation and self-expression do not lie entirely with persons with mental handicap. They spring partly from the low expectations of others, even those with a life-time's experience as family members or professionals.

"The time has come to remove the barriers to greater participation – those that lie within our own attitudes, in families and colleagues and in the community around us."**) ▶

*) *Full Participation of Persons With Mental Handicap*, by Eleanor Elkin (paper given at the symposium).
**) *Participation in Family and Community Life: a position paper*, ILSMH, 1984.

NFPU (Norway)/H Madsen

IS 32

Yes, but . . .

They're not ready yet . . .

What about the people who don't want to be involved?

Think of the people with profound handicaps!

We'd only be creating a meritocracy of mildly handicapped people . . .

How can they claim to speak for others? Professionals will manipulate them for their own ends . . .

We had one on the board but she never said a word . . .

Participation in family life? We've been doing *that* for years . . .

First things first! We're still trying to ensure basic education and involve the parents . . .

The symposium threw up all these reasons and more for not thinking about how to encourage a fuller participation of people with mental handicaps. Delegates showed a fine concern for the ideal of democracy – forgetting perhaps that in reality, what it means in any community is that a few politically active members represent the interests of the many who are inactive. They showed great anxiety for people whose handicaps are profound – forgetting perhaps that they form a tiny minority of those we say have mental handicaps. At times, their arguments echoed fairly exactly, as one delegate from a developing country pointed out, those used by colonial governments against allowing self-determination to indigenous peoples.

But who isn't ready?

- In 1984, People First of Washington State in the USA organised in cooperation with others the first ever international self-advocacy leadership conference. Two hundred self-advocates and advices from Canada, New Zealand, Australia and England as well as 25 American states, came together to share ideas, materials and leadership skills. People First have also produced a newsletter, and guidelines for members on how to rent an apartment, stand up for themselves and conduct meetings.

- In Vienna, three people with mental handicap addressed the United Nations Consultative Committee on the International Year of Disabled Persons to ensure that their concerns were heard.

- Reinforce, the Victoria (Australia) Union of Intellectually Disadvantaged Citizens, held a national housing conference to discuss getting people out of institutions, community housing and getting involved in decision-making – and produced many recommendations for action.

- In Sweden, three action groups of people with mental handicap who wanted to help each other become more independent went to the Cooperative Business Concern and asked it to put symbols on its goods so that people who couldn't yet read could shop independently – and these are only a few examples!

Let's be realistic!

It won't be everyone with a mental handicap who joins a board, addresses a public meeting or participates in a self-

advocacy group. Sometimes their disabilities will be too severe. Very often, they haven't yet been given the chance to learn the skills involved. Sometimes too they will choose not to participate in their communities in this way – like very many thousands of other citizens in any society. But let's be realistic.

Everyone who has a mental handicap can be helped to participate fully in the life of their family.

Even very young or dependent children can be helped to express choice, even if they cannot speak – between two drinks, two items of clothing, tow toys.

Everyone can learn to extend these areas of choice as they grow and mature.

These are the elements of participation.

How can societies help people with mental handicaps to participate?

● Many local societies in different countries are encouraging people who attend workshops and training centres to form groups to discuss common interests in work and living conditions.

● More and more societies now have board or committee members who have a mental handicap – and more of these are now elected rather than appointed.

People with mental handicaps who are members of the ILSMH's Committee on Participation have made the following recommendations:

1. Consider inviting more than one person with mental handicap to serve on the board. Then it is not so overwhelming. They can support each other.

2. Provide a guide or helper for each self-advocate on the board or committee. Together they can discuss the agenda before meetings; the guide can help with procedure, behaviour and language when necessary.

3. Give people tasks which can be carried out successfully. Make sure they are understood. Don't just assign self-advocates to refreshments.

4. Speak clearly and not too fast.

ILSMH member associations are finding specific ways to help self-advocates. For example:

- In Sweden, people with mental handicaps wanted clearer information about these conditions. ALA (the research foundation of the voluntary association FUB) responded by supporting two writers and a group of self-advocates who produced two booklets. Members of FUB have also arranged study circles for people with mental handicap, to help them develop a positive self-image and make more decisions for themselves.

- In the District of Columbia in the USA, the Association for Retarded Citizens helped people with mental handicaps learn procedures for voting in the 1984 elections.

- In New Zealand, IHC helped people who came to the second national conference for people with mental handicaps to prepare for this through meetings at workshop, local and regional level. Now six people will come to IHC's national committee meetings.

"If we don't believe in self-advocacy, it won't happen. The one thing we know today is that we cannot predict how far a person's decision-making power will go."

"What Happens to My Association When I'm Gone?"

"The human being is the central resource of the system, of the organisation. The clients shall take an active part in the process of change. Even in the age of advanced technology, the inherent potential for development of every human being is the most important basis for the organisation's development. We must find ways to arrange the environment both in our places of work and where we work in our spare time in such a way that we will be stimulated, not stopped, in our development. The clue is that as many members of an organisation as possible must be involved in the developmental process."[1]

In 1982, the Swedish association FUB detected a feeling of discontent among its members and some stagnation at regional and local levels. According to Olov Andersson, it recognised many elements of Wolfensberger's analysis of the problems of an advanced voluntary association:

"As an association becomes older, it becomes more formalised and operates by a more rigid set of rules . . . some of the earlier spurt of enthusiasm and intense personal involvement often diminishes . . . many associations are experiencing severe identity problems . . . they are no longer certain of their goals . . . Too many local associations are still led by the early and founding members and too few are asking: 'What happens to my association when I'm gone'."[2]

What to do?

FUB embarked on a programme of *organisational development*, with the help of Sten Alehammar, an "outside" expert.

The aim: to develop the association in a planned way so that it is able to reach the goals it has set.

As Olov Andersson said, "This may have to do with changes in the organisation of the association. But it has just as much to do with changing attitudes, relationships and communication in the association as it is."

- How do the people who work for FUB perceive its goals? How do they work together? What knowledge do they have? Who are the people who have the confidence of leadership, and what are their attitudes?

"Organisational development has to do with implanting enthusiasm and optimism in the movement, getting the members to feel that what they do is important, and getting the association to believe in its own capacity . . . We have to believe that there are a lot of persons who want to be

[1] *Ideas of Developing Organisations and Ideas of Leadership – Something for Voluntary Organisations?* by Sten Alehammar (paper given at the symposium).

[2] *A Report on Organisational Development of the Swedish Association for the Mentally Retarded (FUB)*, by Olov Andersson (paper given at the symposium).

FUB members and that they are able and wish to do something for the movement. Organisational development is not a goal. It must not be done for its own sake and there are no overall solutions. The goal of the association must always be kept in sight – to maximise the rights and the living conditions for people with mental handicap and their relatives. And it is our own resources we have to rely on; we ourselves have to reach the goals. You cannot expect a voluntary association to be as effective as a public or industrial organisation. But we can learn a lot from the way they develop."

● How can a voluntary association be adapted to meet future challenges?

Computer technology will increase: unless we are able to make this useful for people with mental handicaps, it will simply make it harder for them to get jobs, share information and use public services.

Politicians are becoming less willing to spend money on public sector services; at the same time, the technology of prenatal diagnosis of handicap has never been so advanced. This is a dangerous combination.

Decision-making about people with mental handicaps is being increasingly devolved to local authorities.

There is increasing pressure on voluntary associations to run services themselves, rather than handing them over to the public authorities.

The answers for FUB have to do with
● strengthening their network of local associations and increasing local membership,
● helping their county organisations to cooperate better and do more to coordinate and support local associations,
● finding ways for national FUB to increase its own knowledge so that it can deal with an increasingly advanced society.

But there are no overall answers.

"Each organisation is unique. It takes five to seven years to create a self-renewing organisation."

Some Fundamental Questions About Organisations*)

Aims
Are the members of the organisation really aware of its aims? Are these aims formulated in a way that the individual member can understand? Are they discussed and firmly established among the membership? Are they broken down in a way that can be given concrete form and so evaluated?

Information and communications
Are we aware of how we communicate within the organisation? Do we remember that communication in its most simple form is any form of interaction, and that if we don't pay attention to this, it doesn't matter how sophisticated our communications systems are? How often do we evaluate the way that information passes through the organisation and ensure that the receivers get it in the form and with the content that the senders intended?

Decision-making
Do we really know how decisions are made in the organisation? Do members have an experience of participating? Are there both formal and informal opportunities for decision-making? What is the system for following up decisions once made?

Resource-utilization
Resources are not just quantitive – the amount of money, the number of staff – but qualitative. Do we think of resource-development above all in terms of staff-development? Are we always aware of the staffs' inherent resources? Can we use technology to free staff-members for more qualified tasks?

Evaluation
Do we have any system of evaluation at all? Is it related to the organisation's goal? Which parts of the system do we evaluate? Do we include the work of management? Do we dare to evaluate behaviour and skills by giving feed-back?

The climate for change
How ready is the organisation to change? This will depend on needs, traditions and outer and inner pressures. But it will also depend on obstacles thrown up by individuals or groups within the organisation. Where are the obstacles? And where is the support for change? What are the fears of change?

The capacity to solve problems
Does the organisation have any systematic way of problem-solving? Are the staff trained for this? Does the organisation try to introduce new methods for more creative problem-solving? Is it open to new ideas and ready to reward good solutions? How does it handle conflict: by pretending it doesn't exist or trying to resolve it?

Independence
It is known that organisations which can't make decisions without asking others often function less well than those which are more independent. How independent is the organisation? How self-confident is

*) From: *Ideas of Developing Organisations and Ideas of Leadership.*

it in learning from its own mistakes and successes?

A basis for organisational development
Which of the factors below are most important to the development of an organisation? Try to rank them in order:

In order to develop the organisation:
a) you must shift or find *resources* – time, money, materials etc.,
b) you must try to *survey* its activities and make the current situation known to its members,
c) you must find a way to *evaluate* the work and the social climate,
d) you must ensure the members know the *history*,
e) you must know which and where the *obstacles and support* are,
f) you must have a climate where *experiment, fantasy and fearlessness* are encouraged,
g) you must have a clear ambition to reach *aims*,
h) you must ensure that the members as far as possible understand the *effects of the change*.

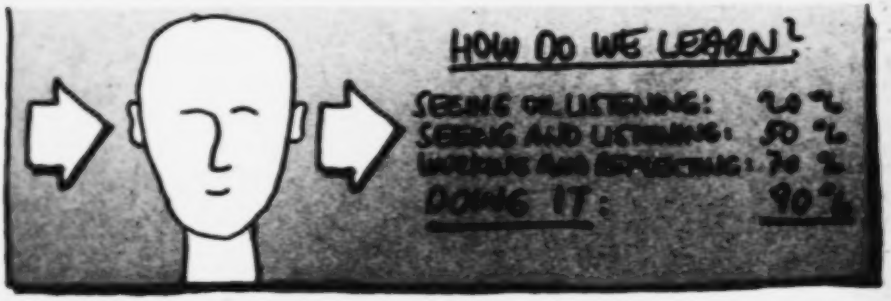
There are no clear answers!
But delegates agreed that it would be hard to start on a process of organisational development without being very clear of the aims, and having a "portrait" of the whole organisation, as well as of the crucial factors that make for an efficient organisation. Knowledge of where the obstacles and support are to be found was seen as important, too.

Organisational development – who needs it?
Delegates to the symposium saw no reason why a process developed in industry shouldn't be of value to voluntary associations. But they weren't slow to see the difficulties, either.

- Attempts to introduce the process will be resisted if a national organisation tries to impose it "from above". But how to carry the organisation with you when, for instance, you have a federal structure of 400 local branches and 100,000 members?

- "Development" may be taken to mean "growth" – and that may be the last thing that the organisation needs.

- There are real differences between profit-oriented, hierarchical commercial organisations and voluntary ones.



Getting Started:
DRAW A MAP OF 'REALITY' - THE ORGANISATION AS IT IS.
DRAW UP 'IDEALS' - THE ORGANISATION AS IT OUGHT TO BE.

Questions of Leadership

"I have the same strong belief in education as Wolfensberger when he speaks of membership education. In the first place, though, I think you have to speak of *leadership* education . . . And when I talk of leadership I am not necessarily referring to one person – the chairman of the board – but also to the team that forms the board.

"I would point to Wolfensberger's discussion about the need for a 'permanent cultural revolution' to keep enthusiasm alive in the voluntary association. Again, this comes back to the importance of leadership. The creation of such a climate in an association is very much dependent on a charismatic type of leadership. And the most dynamic person in a voluntary association is not always the chairman of the board.

"That is why it is so important that we start to work with relationships and attitudes within the team of persons elected to leadership positions."

Olov Andersson

There seems to be a trend to strengthen the importance of leadership, giving it a more active role in activating and stimulating staff to create new ideas and find new ways to do the work. One of the most influential theories of leadership takes the development of individuals and groups as one of its most important ingredients.

This theory says that, in principle, you can manage a group of people in four different ways, according to the group's competance and maturity.

Competance is assessed by four qualities:
- capacity to forumate high and idealistic aims,
- willingness to assume responsibility,
- capacity to take responsibility,
- knowledge of and readiness for the area of interest.

Managers must first make an assessment of the capacity of the group (or individual): a group with high competance has all the above qualities, while a group with low competance has none of them. Then, the management uses the most appropriate style of leadership for the group, by mixing *concern for task* with *concern for relationship*.

- In a group with low competance, the management must focus on getting the job done (high task orientation, low relationship orientation),
- when competance is higher, the style of leadership changes, to give more emotional support (high task orientation combined with high relationship-orientation),
- in a group of still higher competance, there can be more investment in support (low concern for task, high concern for relationship),
- in highly competant or mature groups, the group itself can take over the job (low task-orientation, low relationship-orientation).

This theory also says that one of the manager's most important tasks is to develop the group (or the individual) through a developing leadership style, using the following four steps: telling, selling, participating and delegating (Sten Alehammar).

Thoughts for the Future

How to sum up the symposium? As rapporteur, I am left with a predominant image of associations working against indifference and even hostility from the world "out there". We heard more of the difficulties and doubts of associations – in their very different settings and stages of development – than we did about their very considerable achievements.

That's not, perhaps, suprising. The purpose of the seminar was, after all, not to celebrate the positives of past and present, but rather to try to chart a way ahead into times which, as Gunnar Dybwad said, look to be both difficult and problematic. Many of the people from the "developed" countries, too, brought with them a whole historical baggage of hard struggle to establish and maintain their associations – and that is bound to colour how they live the present and anticipate the future. For the people from "developing" countries, that struggle is most often the present reality. Even in "developed" countries where associations are strong and well-established, as Gunnar Dybwad also made clear, there is no shortage of battles to be fought in these hard economic times. The call to arms becomes both a necessity and an obvious rallying cry.

And yet is this image of battle the only one for ILSMH's member associations to take into the future? Is there a danger that in the demands of the present they may lose sight of the vision of a more positive alternative and even of the belief that that vision can become reality? It can maybe become hard to reach out to potential allies – or even to recognise that they are there.

This isn't at all to deny that there are battles to be fougth: of course there are. But it is to wonder whether associations may be making their task harder than it need be. It's to suggest that expecting only negative answers to the question "If not us, who?" may cut associations off from people who would willingly become engaged in the struggles of people with mental handicap, if they only knew how best to do so. And it is to suggest that a tendency to isolationism among associations may bring the danger of locking people with mental handicaps into the microcosmic world of the association and its affairs and services, rather than encouraging their integration into that wider society "out there".

So as ILSMH's members look towards their future, is there perhaps the need for not just a greater openness to the possibilities of that wider world, but a keener set of strategies for reaching into it and a different balance between looking inwards to their associations' own needs and looking outwards to potential new alliances? And is there too the need for a sharper understanding of the nature of the battles to be fought – battles which have to do with the balance of power and influence among and between organisations rather than among and between individuals?

Looking Inwards, Looking Outwards

The symposium wasn't just about the associations and their development; topics on the agenda included influencing the public, involving young people and professionals in common goals and, most importantly, finding ways to encourage the fuller participation of people with mental handicaps themselves.

Yet the discussion around the involvement of professionals was striking for the strength of feelings it aroused among delegates. And what, for some delegates, those feelings and even anger were about was resistance to the idea that professionals had much of value to contribute at all. There were, of course, the usual phrases about "working together" and "partnership". But there was little deeper discussion on how that cooperation might become more strong and real.

None of us needs telling about the history of antagonisms between parents and professional workers. None of us needs much convincing, either, that there are still far too many professionals who damagingly and consistently use their own ignorance to underestimate the needs and abilities of both parents and people with mental handicaps. But "the professionals" aren't going to go away. So what to do?

To write them off as irredeemable, as a group, seems shortsighted, for the symposium also heard about professional workers who are enabling, sustaining and sometimes quite essential people to the lives of associations. It is also a fact that people with mental handicaps will go on meeting professionals of all disciplines, whether they are all those good things or not, and that professional power in their lives will not evaporate. So is it one of the tasks of associations, as Ron Major suggested, to seek out in a deliberate and structured way, the potential allies among "the professionals" and to work with them to turn potential into actuality? Do associations also have the responsibility to discriminate more carefully between those professionals who are just plain ignorant – and so could gain from educational campaigns – and those who are so caught in their own professional histories and traditions that they have to be circumvented, their power as far as possible neutralised? If so, these are battles that call for careful strategies; blunderbusses just won't do.

If relationships with professional people can raise most clearly the dangers of isolationism among associations, the symposium also threw up other examples of how negative expectations may be limiting their discovery and encouragement of allies. It's perhaps significant that the symposium had no discussion at all on how to involve young people in the future; the possibilities of Citizen Advocacy, for instance, which Wolfensberger saw as a significant way of drawing in "new blood", were not even mentioned. Yet in the nature of things, many people with mental handicaps are people who are young. If the goal is really to enable them to lead "as normal a life as possible", closer relationship with their peers looks like being one of the most important routes for getting there. So how ready will associations be – in the discussions which the symposium agreed are needed on this topic – to systematically work out ways in which young people

who are not parents can be drawn in as allies? And what should be the nature of the alliance, when so often associations have drawn their strength from being, very precisely, organisations above all of *parents*?

"Outsiders" don't just bring new energy into associations and widen the social networks within which people with mental handicaps can easily move. They also bring new perspectives, which are sometimes closer to those of the world "out there" than those of the association itself. That can be valuable: as the symposium heard more than once, associations need to be sure that their own philosophy is not too far out of line with that of the wider society if they want their work to succeed (though maybe not too far in line, either, if they want to remain agents of change). But the perspective of "outsiders" can be challenging, too. So, another question: how far are associations ready to open themselves to this?

"Yes, but we're doing that already" may, for instance, be a perfectly truthful response to the suggestion that the expertise and techniques of organisational development, as it has grown up in industry and commerce, may have something to offer voluntary associations. Yet it may also mask a reluctance to open the association to a new sort of scrutiny. It's worth noting here, perhaps, that the symposium touched hardly at all on the topic of monitoring the quality of services – and that means those run by the associations themselves every bit as much as, if not more than, those run by government and other agencies. Yet as Gunnar Dybwad emphasised, this is a critical task for the 1980s (and one which, in light of the symposium's discussions, is now high on the list of ILSMH's priorities).

Finally, and perhaps most importantly, how ready are associations to open themselves to a new and challenging source of monitoring – that brought by the people who use the services themselves? If the emotional temperature of the symposium rose during the discussion on professionals, then it rose several degrees higher during that on participation by people with mental handicaps.

The challenge of self-advocacy is only now becoming urgent, as individuals with mental handicap are forming groups to press their own aims and aspirations. What was striking during the discussion was how far the reluctance among some participants to recognise the importance and validity of these echoed the very attitudes that parents have criticised among professionals across the years. There is the same tendency to low expectations, the same failure to trust the perceptions of the other. Professionals may say parents "aren't ready" to meet other parents; parents can say too that people with mental handicaps "aren't ready" for fuller participation. Professionals may "need" the notion of people with profound handicaps to justify traditional institutional practices; parents, it seems, may "need" that notion too, to justify traditions of protection. "Fuller participation in family life" may be a comfortable notion – especially if "we're doing that already"; fuller participation in that world "out there" may be less easy to envisage.

Yet ILSMH's commitment to enabling that fuller participation is there, and so the questions demand some answers. How are associations to help people with men-

tal handicaps realise their aspirations for self-determination? What are the precise mechanisms of support that associations can offer? Where are the forums in which the role of advisors can be discussed with the people who might want to avail themselves of what they offer? And in this new and challenging dimension of the politics of mental handicap, what sort of a balance of power is there to be between those who have traditionally "spoken for those who can't speak for themselves" and those who are now beginning to find their own and distinct voice?

From Individual to Organisation

The politics of mental handicap – in which all associations are inevitably engaged, whether they are, in Wolfensberger's terms, "first-stagers" or "third-stagers" – have to do with more than alliances and battles between individuals. Associations will continue to have links with individual "outsiders"; they will continue to provide a representative for "outside" boards and committees, set up by government and others. But political life has also to do with questions of power and influence among and between organisations as well. How ready are associations to see alliances and battles at this, rather than the individual, level?

In the Caribbean, for instance, as the symposium heard, they are now talking increasingly of the forging of alliances with different disability groups and organisations to fight for common goals, rather than "going it alone". How far is this a way ahead elsewhere?

The formation of organisational alliances certainly strengthens the power base: a single organisation pressing for change is less likely to be heeded than an alliance of different organisations – especially if it unites, say, the representative bodies of such traditional "enemies" as parents and doctors. Organisational approaches can be more effective at spreading messages: while an educational programme for a group of medical students, for instance, may have its effect, that effect can be hugely multiplied if the programme is agreed between the association and the country's major medical organisations as a necessary part of the curriculum in every medical school. Organisational approaches may also bring practical results: while amassing individual examples of people with mental handicaps who are holding down regular jobs may have an important effect in encouraging individual employers, organisational alliances between voluntary associations and trades unions and employers' federations may go further than that in changing expectations and even employment laws.

Alliances of this organisational sort are unlikely to be for all time; they may coalesce around a single issue and break apart again over policy differences. But does their transitory nature matter? Wolfensberger wrote in his 1973 paper of the need for a *single* body which spoke for people with mental handicaps who cannot speak for themselves. But is that an example now of an isolationism that associations can no longer afford in a world where strengthening the power base and the extent of influence is not

going to become any less important – and a world too where we are seeing in many countries a plurality of different organisations springing up on behalf of people with mental handicaps? The spread of interest and involvement is surely to be rejoiced over rather than stamped on. But it raises its own questions of ensuring a united voice when it is needed. How ready are the associations to address themselves to these issues of organisational politics?

And how ready are they to see the new organisations of people with mental handicaps as part of these questions? Members of the ILSMH Committee on Participation who have mental handicaps have reinforced the Nairobi recommendations for stronger representation of people with mental handicaps on association board and committees. But many people with mental handicaps as they also emphasise want their own organisations as well. Self-advocacy, as the symposium agreed, has to do not just with individuals speaking out about their lives and aspirations, but about the forming of a group consciousness.

This is the beginning of becoming a political force. It will be a force that is independent of organisations of parents and friends. Sometimes it will be in alliance with them. Sometimes it will not. Of all the challenges that lie ahead, this is perhaps the one which will most fundamentally test the firmness of ILSMH's resolve to enable people with mental handicaps to take their rightful place in their societies. Yet isn't it also the one which will bring the greatest rewards, and as it develops, point most clearly the way ahead?

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The International League of Societies for Persons With Mental Handicap. Founded in 1960 by representatives of societies of parents of mentally handicapped persons, friends, and professionals in the field of mental retardation, the ILSMH is devoted to defending the rights and interests of mentally handicapped persons without regard to nationality, race, or religion. The League addresses problems related to mental retardation: among them are prevention, diagnosis and early treatment; education and training; economic security; social welfare and integration; guardianship; interfamilial relations; due process of law and public education.

In order to achieve these objectives, the League, with the help of its member societies, organizes international symposia of experts, regional conferences, and world congresses. The League publishes the results of these efforts, an international newsletter translated in four languages, and various pamphlets on topics of general interest. The League has consultative status with UNESCO, ILO, WHO, ECOSOC, and the Council of Europe, and has official relations with other international organizations interested in handicapped persons.

Looking Forward
A report on an ILSMH symposium on the future role of voluntary associations

Madrid, November 1984

By Ann Shearer

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